

Fall prevention for people with learning disabilities: key points and recommendations for practitioners and researchers

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**FALL PREVENTION FOR PEOPLE WITH LEARNING DISABILITIES: KEY
POINTS AND RECOMMENDATIONS FOR PRACTITIONERS AND
RESEARCHERS**

Overview

This article provides a narrative review of what is currently known about the high rates of falls, and fall injuries, which are experienced by people with learning disabilities. Current evidence is presented throughout the article as key points and recommendations for practitioners and researchers. The literature included in this review is presented according to the four key steps of a public health approach applied to fall prevention (Mercy *et al.*, 1993) (See Table 1).

*****Insert *table 1* about here*****

Research on rates of falls and fall injuries help to increase understanding of the magnitude, scope and characteristics of falls experienced by people with learning disabilities (LDs) (step one). Studies of risk factors are an important step two, informing the development and evaluation of interventions and services to prevent further falls (step three). Annual health checks and development of a consensus-led approach to fall prevention for people with LDs are then given wider consideration, in relation to improving the quality of evidence and implementing strategies to prevent falls on a broader scale (step four).

Highlighting the problem

Recent, longitudinal studies (Sherrard *et al.*, 2001; Finlayson *et al.*, 2010; Hsieh *et al.*, 2012; Petropoulou *et al.*, 2016; Foran *et al.*, 2016) have enabled us to confirm high rates of falls amongst people with LDs of all ages. People with LDs (or intellectual disabilities, which is the internationally recognised term) are defined as having, ‘a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence), which results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood’ (World Health Organization, 2010). There is already a plethora of evidence on falls and their consequences amongst older adults without LDs in the wider population, but it is only now, when we know the extent of the problem is comparatively the same, that we can raise awareness, and address the need to develop fall prevention strategies and interventions for people with LDs as well.

Falls are common

Between 25% and 40% of people with LDs experience at least one fall per year (Sherrard *et al.*, 2001; Finlayson *et al.*, 2010; Cox *et al.*, 2010; Hsieh *et al.*, 2012; Petropoulou *et al.*, 2016). This means that they are experiencing similarly high rates of falls as older adults in the wider population, of which around 30% fall each year (National Institute for Health Care and Excellence, 2013), but throughout their lives.

The majority of people with LDs live in their own communities, on their own, with their families or with paid support (World Health Organization, 2010). All aforementioned studies therefore, are based on community-based samples. Other studies on falls amongst adults with

LDs who live in congregate care have reported rates of between 27% and 28% of the sample over a 3 to 6 month period (Chiba *et al.*, 2009; Pal *et al.*, 2014), 35% over a 12-month period (Salb *et al.*, 2015), and between 61% and 70% over a 33-month to 5-year period (Grant *et al.*, 2001; Wagemans and Cluitmans, 2006).

Falls and ageing

People with LDs are also an ageing population. As their life expectancy increases (Hermans and Evenhuis, 2014), more may be prone to falls and fall injuries as they age, just like the wider population. A previous study of 78 older adults with mild to moderate LDs (aged 50 years and over) in the Netherlands found that, in a 12-month period, 46% had experienced at least one fall, of which 76% had resulted in injury (Enkelaar *et al.*, 2013). However, Foran *et al.*'s (2016) population-based longitudinal study of 753 older adults with LDs (aged 50 years and over) in Ireland found that only 27% had experienced at least one fall in the previous 12 months, of which 16% had experienced two or more falls.

It is commonly understood that people with LDs may be considered 'older adults' from the age of 50 onwards, due to earlier occurrence of frailty (Hermans and Evenhuis, 2014). Interestingly, Foran *et al.* (2016) found that those within the 50 – 64 year age category were twice as likely to fall, compared to those aged 64 years and over. Fall prevention strategies and interventions for older adults with LDs should, therefore, be targeted appropriately for people aged 50 years and over. This should include equity of access to fall prevention services which are currently targeted more towards older adults aged 65 years and over in the wider population.

Consequences of falling

Falls are a serious problem for people with LDs because of their potential consequences.

These may include loss of confidence, injury and death.

Impact of falls

There is a dearth of qualitative literature available on the psychological impact of falls on people with LDs. One Australian study by Cahill *et al.* (2014), conducted with nine adults with mild to severe LDs, demonstrated that impact was relative to the degree of insight gained following a fall; those with insight into the potential causes and risks of falling made self-imposed changes in their behaviour (e.g. activity modification, or increased reliance on people or aids for support) while those with little or no insight did not. Finlayson *et al.* (2014) conducted qualitative interviews with ten adults with LDs (and their family or paid carers), who had been frequently or seriously injured in the previous 12 months; seven of the adults had experienced frequent falls and/or a serious fall injury. In terms of impact, fear of walking outdoors unsupported was reported by one individual with LDs following a serious fall injury, rather than fear of falling per se. Family carers in both studies reported stress (Cahill *et al.*, 2014) and constant fear and worry (Finlayson *et al.*, 2014), as a result of their relative with LDs experiencing falls and/or fall injury. The literature on older adults in the wider population already emphasises the importance of including carers in fall prevention interventions, to reduce their fears and worry and to increase their competence to cope with and prevent fall injuries (Faes *et al.*, 2013).

Fall injuries

Previous research has shown that children and adults with LDs are twice as likely to experience an injury (from any cause), when compared to the wider population (Sherrard *et al.*, 2001; Finlayson *et al.*, 2010; Petropoulou *et al.*, 2016), and between six and eight times more likely to die as a result of their injury (Dupont *et al.*, 1987; Strauss *et al.*, 1998; Sherrard *et al.*, 2001; Durvasula *et al.*, 2002). Falls are the leading cause of injury for people with LDs (Sherrard *et al.*, 2001; Finlayson *et al.*, 2010; Petropoulou *et al.*, 2016). The studies by Sherrard *et al.* (2001) in Australia and Finlayson *et al.* (2010) in Scotland are, to date, the only two population-based injury studies that have made comparisons with the wider population over a 12-month period to determine relative prevalence. The study by Petropoulou *et al.* (2016) also compares injury rates reported for Scottish adults with LDs who live in supported living settings and the wider population over a 12-month period. The earlier studies by Dupont *et al.* (1987) in Denmark, Strauss *et al.* (1998) in the United States, and Durvasula *et al.* (2002) in Australia are based on secondary analysis of national or state registers only, but these studies were important in highlighting the problem and the potentially fatal consequences of falls. Around one-third of falls reported for people with LDs result in injury (Cox *et al.*, 2010; Hsieh *et al.*, 2012).

Falls and fractures

The most common types of fall injury reported for people with LDs are superficial i.e. cuts and grazes (Finlayson *et al.*, 2010; Petropoulou *et al.*, 2016), but they do experience higher rates of fractures when compared to the general population. Recent research has demonstrated, for example, that femoral fractures can occur 10 – 15 years earlier in women with LDs, compared to the wider population, and 20 – 40 years earlier in men with LDs (Buchele *et al.*, 2017). People with LDs are also a high-risk population for developing

osteoporosis which increases fracture risk, due to a number of factors more prevalent in this population including having Down's syndrome, being prescribed anti-epileptic drugs, and immobility (Srikanth *et al.*, 2011). One previous study conducted in the United Kingdom, for example, found that 16 (89%) out of 18 adults with LDs, identified as having one or more of these risk factors, were found to have osteopenia/osteoporosis following Dual-Energy X-Ray Absorptiometry (DXA) bone density assessment (which is the gold standard for assessment/screening) (Srikanth *et al.*, 2011). It is important therefore, that tailored osteoporosis assessment, screening and management are considered for and available to people with LDs, to prevent serious fall injuries.

Risk factors

Risk factors for falls

It is difficult to draw meaningful comparisons from the as yet limited literature on risk factors for falls amongst people with LDs (Hsieh *et al.*, 2001; Grant *et al.*, 2001; Sherrard *et al.*, 2002; Wagemans & Cluitmans, 2006; Chiba *et al.*, 2009; Cox *et al.*, 2010; Finlayson *et al.*, 2010; Hsieh *et al.*, 2012; Enkelaar *et al.*, 2013; Salb *et al.*, 2015), due to the wide variation between studies in sampling, methods, and choice of variables tested. Table 2 lists those factors found, though not always consistently, to be associated with fall risk in the literature on people with LDs. These factors require fuller investigation and replication in prospective, population-based studies. The list given in Table 2 seems unlikely to be comprehensive.

*****Insert *table 2* about here*****

Falls and the environment

People with LDs can fall at home or outdoors, and it is important to consider other internal and external environmental factors which are not listed in Table 2. These factors may include for example, stairs or steps, rugs, low lighting, and transient hazards (e.g. uneven ground surfaces or out-of-place chairs) (Cahill *et al.*, 2014).

Risk factors for fall injuries

Two prospective population-based studies have both identified epilepsy and urinary incontinence as predictive risk factors for fall injuries (Finlayson *et al.*, 2010; Hsieh *et al.*, 2012).

Epilepsy

People with LDs, particularly people with moderate to severe LDs, can be up to fifty times more likely to experience epilepsy, compared to the wider population (Lhatoo *et al.*, 2001). It is hardly surprising, therefore, that epilepsy is highlighted as a particular risk factor for fall injury in this population. People with LDs and epilepsy can experience seizure falls, and the presence of epilepsy (or the use of antiepileptic drugs) can increase the risk of non-seizure falls and fall injury, especially fractures. Fall prevention strategies and interventions for people with LDs require effective epilepsy management with regular review within care and support services (including the needs to provide safe environments and monitor side-effects of anti-epileptic drugs). Awareness of the much higher prevalence of epilepsy, and other health conditions which can contribute to falls (e.g. visual impairment), is also required

within fall prevention services for the whole population, which, as already mentioned, people with LDs should be equally entitled to use.

Urinary incontinence

It is not yet known how urinary incontinence increases the risk of fall injury for people with LDs. Mixed incontinence (which is a mixture of both urge and stress incontinence) has been established as a risk factor for falls in older adults in the wider population (Foley *et al.*, 2012). However, whilst this may also be true for older adults with mild LDs, whose patterns of health are similar to those in the wider population, it is unlikely to be the case for people with more severe LDs (with long-standing continence issues). As well as increasing the risk of fall injury (Finlayson *et al.*, 2010; Hsieh *et al.*, 2012), urinary incontinence has been identified as an independent risk factor for mental health problems in adults with LDs, and behaviours that challenge (von Gontard *et al.*, 2016). Urinary incontinence as a risk factor, therefore, may be related to a third or underlying factor that has not yet been identified (e.g. a common mechanism, severity of LDs, or complexity of needs).

Urinary incontinence is a common problem for people with LDs, and it is one of those issues that can be overlooked due to ‘diagnostic overshadowing’; in other words, not treating an issue that is just seen as part of the person’s LD (Nash, 2013). A recent review of incontinence management for children and adults with LDs, however, has demonstrated that effective incontinence assessment and treatment could and should be realised for people with LDs, both children and adults (von Gontard *et al.*, 2016).

Individual risk assessment

The reasons older adults in the wider population fall are often multi-factorial and individual to the person (World Health Organization, 2008). The reasons people with LDs fall may also be multifactorial, and fall prevention for people with LDs does require individual risk assessment.

For those who provide care or support to people with LDs, it is important that individual fall risk assessment is incorporated routinely into care/support planning for all people with LDs, or at the very least, for individuals with LDs who have experienced more than one fall or at least one fall injury (Finlayson *et al.*, 2015; Petropoulou *et al.*, 2016). National Institute for Health Care and Excellence (NICE, 2013) guidelines are available on fall risk assessment. At the same time, it is important that opportunities continue to be offered to individuals with LDs within a positive risk-taking and risk reduction framework (Finlayson *et al.*, 2015). In other words, individuals with LDs who are identified as being at risk of falling, and/or of experiencing a fall injury, should not be restricted by these risks but be carefully and ‘actively’ (Wilson *et al.*, 2010) supported to overcome them in their everyday lives, through the use of counter measures.

Fall prevention strategies and interventions

A previous review of the literature on balance and gait issues in people with LDs has demonstrated an important relationship between falls and balance and gait issues (Enkelaar *et al.*, 2012). People with LDs aged 50 years and over, for example, have been found to have balance capabilities similar to those of adults in the wider population who are twenty years

older (Oppewal *et al.*, 2013). Exercises to improve or maintain strength and balance for people with LDs are likely to be central to developing effective fall prevention.

Two evaluations of falls services for people with LDs are available (Smulders *et al.*, 2013; Crockett *et al.*, 2015), in which strength and balance exercises were prescribed to reduce falls. Seventy per cent of the participants with LDs were prescribed exercise within a Physiotherapy-led falls service in Scotland (Crockett *et al.*, 2015) – which led to significant improvements in balance and gait and reduction in number of falls recorded – compared to only 23% of participants with LDs who attended a non-Physiotherapy-led falls clinic in the Netherlands (Smulders *et al.*, 2013). A multi-disciplinary approach that involves working closely with practitioners – especially physiotherapists and occupational therapists– is likely to be important in realising effective fall prevention for people with LDs.

Pal *et al.* (2013) conducted a qualitative study with eight physiotherapists and occupational therapists in New Zealand, to learn about their views and experiences of trying to reduce fall risk for their clients with LDs. These practitioners identified the following four themes as being most important for developing fall prevention strategies:

- Environmental modification;
- Participation in physical activity and exercise;
- Prescription of assistive mobility devices; and
- Education on safe mobility.

Finlayson *et al.* (2015; 2014) have also stressed the importance of adequate provision of aids and adaptations for people with LDs (e.g. hand rails, non-slip floor surfaces, spectacles,

hearing aids), including assistive mobility devices, to prevent injury as well as regular checks by practitioners to ensure they are being used and used correctly.

Annual health checks

People with LDs experience high rates of health problems, compared to the wider population, and can experience barriers to accessing appropriate health care and inclusion in health promotion initiatives (Robertson *et al.*, 2014). Many of these health problems can, in turn, increase the risk of individuals experiencing further health and wellbeing issues, such as falls, and behaviours that challenge. Urinary incontinence has already been provided as an example to demonstrate this. Internationally, annual health checks are recommended for people with LDs to identify and address their health needs (Robertson *et al.*, 2014). Annual health checks are recommended for people with LDs in this article, to improve their overall health and wellbeing, and thus lessen poor health factors that can contribute to or cause falls. Annual health check assessment tools that additionally consider fall/injury risk and occurrence would be most beneficial (Bakker-van Gijssel *et al.*, 2017), with regards to implementing interventions that contribute towards fall prevention for people with LDs on a broad scale (step four of the public health approach).

Developing a consensus

It is difficult to draw meaningful comparisons between studies in the literature due to wide variation in samples and methods used. For example, whilst some studies have investigated people across all levels of LDs (Sherrard *et al.*, 2001; Cox *et al.*, 2010; Finlayson *et al.*, 2010), others have excluded adults with severe or profound LDs, or wheelchair users, or

those with epilepsy (Enkelaar *et al.*, 2013, Smulders *et al.*, 2013). As mentioned earlier, people with LDs and epilepsy can still experience non-seizure falls and be at increased risk of fractures due to side effects of anti-epileptic medication. It is better to include people with epilepsy in studies but distinguish between non-seizure and seizure falls during data collection and analysis. In terms of measuring poor balance or gait issues, variation in physical outcome measures is also evident (Chiba *et al.*, 2009; Enkelaar *et al.*, 2013; Oppewal *et al.*, 2013), and in two studies the carer's opinion of whether the person they care for/support has poor balance or coordination was the only measure included (Finlayson *et al.*, 2010; Pal *et al.*, 2014).

In 2005, Lamb *et al.*, on behalf of the Prevention of Falls Network Europe (PROFANE), published a consensus methodology for developing falls prevention strategies and interventions for older adults in the wider population, to ensure collaborative working towards developing best quality of evidence. It may be timely – whilst the literature is emerging - for researchers and research-active practitioners in the field of LDs to consider working collaboratively towards the same. A consensus-based approach ensures 'focus on carefully defined problems that can be investigated in a timely and economical way' (Fink *et al.*, 1984, p.981).

Conclusion

The vastness of literature on falls in older adults in the wider population illustrates the seriousness of the issue. We now know that people with LDs experience similar rates of falls as older adults in the wider population, but throughout their lives. Falls are not necessarily a normal part of ageing, nor are they a necessary consequence of a person having LDs.

Strategies and interventions to prevent falls in people with LDs are warranted, with an emphasis on close working between researchers and multi-disciplinary practitioners to develop best, evidence-based practice. Raising awareness amongst practitioners who work in non-specialist LD services is also recommended, to ensure people with LDs can reasonably and equitably access these services. Finally, it is recommended that researchers in the field begin working towards developing a consensus methodology to ensure that the evidence gathered is of universally, and comparably, good quality.

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Table 1: The four key steps in a public health approach to fall prevention

Step 1	Determine the magnitude, scope and characteristics of the problem.
Step 2	Identify factors that increase the risk of falling and fall injury, to determine which factors are potentially modifiable.
Step 3	Assess what measures can be taken to prevent the problem, by using information acquired in step 2 to design, pilot-test, and evaluate interventions.
Step 4	Implement the most promising interventions on a broad scale.

Table 2: List of factors associated with fall risk in the literature on people with LDs

Personal, Biological and Medical (including prescribed drugs): <ul style="list-style-type: none"> • Being female • Advancing age • Down's syndrome (protective factor)* • LD level (mild, moderate, severe or profound)** • Epilepsy • Paretic conditions or cerebral palsy • Arthritis • Heart condition • Back pain • Dizziness or hypotension • Visual impairment • Urinary incontinence • Previous fractures • Polypharmacy • Anti-epileptic drugs
Physical and Behavioural: <ul style="list-style-type: none"> • Balance or gait issues • Reduced or impaired mobility (including use of walking aids) • Problem behaviour/s • Fear of falling*** • History of falls • Being clumsy or accident-prone • Poorly fitting shoes
Lifestyle and Environmental: <ul style="list-style-type: none"> • Physical activity level (either being physically active or being sedentary) • Winter (season)

* People with Down's syndrome have a lower risk of falls than other people with LDs.

** Different studies have identified different groups to be at higher risk.

***Fear of falling has yet to more fully emerge as a risk factor, but will likely do so in future studies using fear of falling assessment tailored specifically for use with people with LDs (Foran, 2013).